



Top Things...

You wish your service coordinator knew, understood, would do, or would stop doing!



A group of Tennessee parents were asked to provide their thoughts about how they would advise service coordinators when it comes to assisting families entering the early intervention system. Their suggestions should prove helpful in building effective partnerships with families.

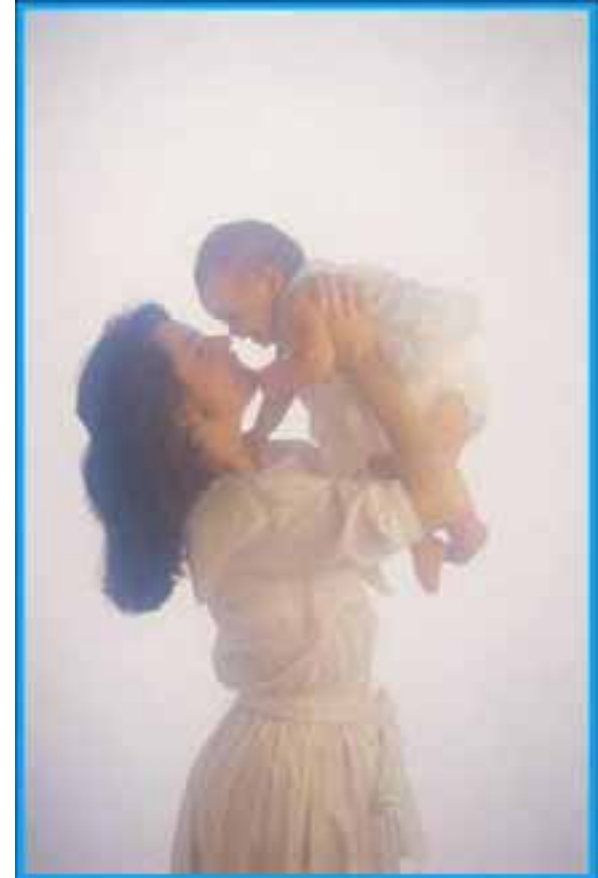


- By helping me understand my child's special needs, you help me learn why early intervention services are important.
- Big, scary sounding words do not help us when we may already be feeling frightened. As often as possible, avoid words that are unnatural and not used in everyday language.
- Never attempt to give a prognosis about a child, even if you have seen many like ours. Children are known for surprising us.





- We may need time to adjust to a diagnosis or a medical prognosis before we can be open to your assistance.
- Develop and show patience and compassion.
- Always remember that our children are our most precious treasure. Treat them as such.





- Find the positive in every child, and build on that.
- Just because we don't do things the way you or others would do them, doesn't mean that we are a bad family. Avoid being judgmental.
- Love your job. It will make things better for everyone.
- Communicate with us about community resources and programs that are available.





- As you share resources and service information, help us to understand that we will determine what is manageable and right for our child and family.
- Let us know that we have time to think about what is available, and that we can get back to the service coordinator if we would rather not commit to a particular service right away.





- Make referrals in a timely manner, and contact me at least monthly.
- Help us understand the “team approach” to addressing our child’s needs.
- In the beginning, I was hungry for information. Help me learn all I can.
- Understand that what seemed like a priority today, could change in 24 hours.





- Do not downplay the importance of getting a diagnosis for children. A lot of professionals, including the service coordinator told me it didn't really matter that local physicians were unable to provide a diagnosis. They said the treatments of the symptoms (speech, occupational, and physical therapy) would be the same regardless of the diagnosis. That may hold true for some disorders, but my son had autism, and he would definitely have benefited from having appropriate early intervention services specific to autism.





- Thoroughly understand funding regulations. I had a six-month-old baby who was undergoing surgery, and I needed to know how private and public insurance funding worked. It would have been very helpful to have help in figuring this out while I tried to prepare for surgery, take care of my baby, and work full-time.
- Be certain of the accuracy of your advice before you offer it.





- My family life seemed to revolve around my daughter who has special needs. It was helpful to have other professionals remind me of the big picture – that I did have other children.
- Therapists, doctors, and professionals don't always agree. This can make priority-setting and decision-making very difficult. Often decisions have to wait.
- Getting the appropriate equipment can be very difficult. The process is very confusing. That first wheelchair or pair of glasses can really impact the reality of the condition. Be sensitive to my feelings.





- As a parent, I have experienced so many different emotions. Just when I think I have it all together, I fall apart again. Chronic grief is so hard to understand and control. Patience is so important. Parents need time to adjust.
- Understand that no matter what services we participate in, our children are still going to develop at their own rate.
- Knowing I had someone to talk to, someone who could help me find answers was beneficial to my ability to cope.





- Transition from early intervention, with family-centered services, to an educational system can be a shock to a parent. Letting your child go to a different system can be taxing. Your feelings of uncertainty at this time are almost the same as when you first realized your child had special needs. Understand that it was another trip through the grief process for me.
- Before the first IFSP meeting, explain to the parents that they will be given a chance to express concerns, strengths, weaknesses, etc. The first session is very unnerving, and not being prepared for the first question can leave families feeling inadequate.



As I look back over the years, I know that early intervention services were just as important for my family's development, as they were for my daughter's development. The information we received set us on a path of understanding that has made the experience so valuable to me.

The other key was all the stimulation it brought to my daughter. I know this gave her a good foundation. It could not change the physical impairments that she has, but it made our experiences and quality of life the best it could be. I think she is happy and content with who she is, and I feel good about our experiences. It was not perfect, but nothing in life is.



This time is such a short time in the life of a family. The strength I gained during that time has stayed with me forever. I don't remember many of the details. I do remember the empowering comments I received and the feeling of love and support I can carry for a lifetime.

